

NETWORK NEWS

News from the Utah Birth Defect Network

<http://health.utah.gov/birthdefect>

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Notes from the UBDN Director

What is the "Champion Model"?

During the development of the Utah Birth Defect Network (UBDN), many birth defect surveillance systems, both national and international, were evaluated. The UBDN has been partially modeled on a regional birth defect registry in Spain. Each hospital in the regional registry has a physician responsible for the examination and reporting of infants with birth defects. This approach establishes a consistent method for the clinical assessment of each infant, with documentation.

During the first meeting of the UBDN in 1994, this model was presented and the word "Champion" was suggested to refer to the physician or nurse in each hospital who would actively report any baby born with a diagnosed or

suspected birth defect. During 1994, a Champion was located for every Utah delivery hospital and the model was incorporated into the UBDN. The clinical review for the UBDN is performed by one of two clinical geneticists after all the data abstraction has been completed.

Since the recruitment of UBDN Champions, multiple sources for identifying potential cases with birth defects have been established to ensure all possible cases are identified. Although keeping abreast of changes within communities statewide is time consuming, it is important to keep the Champion model alive and functioning. Not only do Champions serve a vital role as a reporting source for the UBDN, they are important for information dissemination to their respective communities. Champions may use the UBDN as a resource should they, or

the families they represent, need information, referrals or have questions about an infant's birth defect(s).

Over the past year, the UBDN has been conducting outreach activities with current Champions, sending them an information packet containing materials about UBDN activities, procedures, and contact information. The UBDN appreciates all those Champions who have either worked with us in the past or are currently working with us to monitor the occurrence of birth defects in Utah, and provide outreach and education for families.

Marcia Feldkamp P.A., MSPH
UBDN Director



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Update on UBDN Surveillance

In early 2003, the Utah Birth Defect Network (UBDN) began preparing for the nation-wide April 14th implementation of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). With the assistance of the Utah Department of Health's (UDOH) legal counsel, the UBDN evaluated the impact of HIPAA on its public health surveillance activities. It was determined that HIPAA would not affect the UBDN directly but rather how it works with other organizations that are "covered entities." The main concern identified was healthcare facilities' increased burden under HIPAA to account for the access to and release of protected health information to the UBDN—a non-covered entity—

as required by Utah's Administrative Rule R398-5 for birth defect reporting.

Accordingly, the UBDN decided to take a proactive approach to addressing this issue for interacting with covered entities in the state. The UBDN upgraded its documentation, correspondence, and procedures to ensure that they included the necessary information to document disclosures to a public health authority and were HIPAA-compliant. In addition, the UBDN surveillance team met with Health Information Management (HIM) directors and their staff across the state to develop a customized protocol for conducting public

health surveillance activities with each of them. As of April 2004, these HIPAA-related changes have been fully implemented and are now "standard operating procedures" for the UBDN.

The UBDN surveillance team would like to thank the HIM departments in hospitals across the state for their cooperation in making these adjustments and their continued commitment in assisting the UBDN with monitoring birth defects in Utah.

Lynne MacLeod, M.Stat.
Surveillance Coordinator



From the Outreach Desk

The Utah Birth Defect Network has continued to work on the campaign to increase education, awareness and consumption of folic acid among women of childbearing age. The purpose of this campaign is to prevent the occurrence and recurrence of neural tube defects (NTD's). ***Since 1993, NTD's have decreased 30% in Utah.*** While this decrease demonstrates a success, education for women in their childbearing years still must continue. Utah health care providers play a key role in educating women and families. More women need to consume a daily multivitamin with folic acid, whether or not they are planning a pregnancy. Utah data demonstrate women are more likely to take a multivitamin supplement with folic acid ***if advised to do so by their health care provider.***

Prevention efforts offer hope for reducing the number of families in Utah affected by birth defects. The UBDN in conjunction with the Utah Department of Health recommends the following prevention strategies, which can easily be incorporated into a health care provider's practice.

- *Provide folic acid education as a standard of care. The U.S. Public Health Service recommends that all women of childbearing age consume 400 micrograms (400 mcg or 0.4 mg) of folic acid every day to prevent up to 70 % of neural tube defects in the U.S.*
- *Counsel patients to plan their pregnancies and to reduce or eliminate high-risk behaviors that lead to poor birth outcomes.*

You can make a difference in the lives of Utah families! The UBDN has free

information about birth defects and prevention information. Please take advantage of this opportunity to give your female patients up-to-date information about how to prevent birth defects. Should you have questions, please contact me at 257-0566 ext 204 or email anance@utah.gov.

Amy Nance, B.S.
Center Coordinator





West Nile Virus in Pregnancy

Screening During Pregnancy

No specific treatment for WNV infection exists, and the consequences of WNV infection during pregnancy have not been well defined. For these reasons, screening of asymptomatic women for WNV infection is not recommended.

Diagnosis of West Nile Virus Infection During Pregnancy

Pregnant women who have meningitis, encephalitis, acute flaccid paralysis, or unexplained fever in an area of ongoing WNV transmission should have serum (and CSF, if clinically indicated) tested for antibody to WNV. The preferred serologic test of serum and CSF is West Nile Virus IgG and IgM by MAC-Elisa. Testing is available in Utah through ARUP and the Utah Public Health laboratory (only test performed is IgM at this lab). If serologic or other laboratory test indicate recent infection with WNV, these infections should be reported to the Utah Department of Health, and the women should be followed to determine the outcomes of their pregnancies. Only 20% of people infected with WNV have symptoms.

Evaluation of the Fetus in Pregnant Women with WNV Infection

If WNV illness is diagnosed during pregnancy, a detailed ultrasound examination of the fetus to evaluate for

structural abnormalities should be considered no sooner than 2-4 weeks after onset of WNV illness in the mother, unless earlier examination is otherwise indicated. While adverse effects on the fetus are not well characterized, there have been reports of central nervous system complications. Referral to a specialized perinatal center for a detailed ultrasound examination should be considered. Amniotic fluid, chorionic villi, or fetal serum can be tested for evidence of WNV infection. In case of miscarriage or stillbirth, testing of all products of conception (e.g., placenta and umbilical cord) for evidence of WNV infection is advised to document the effects of WNV infection on pregnancy outcome.

Evaluation of Infants Born to Mothers Infected with WNV During Pregnancy

When an infant is born to a mother who was known or suspected to have WNV infection during pregnancy, clinical evaluation is recommended. Further evaluation should be considered if any clinical abnormality is identified or if laboratory testing indicates that an infant might have congenital WNV infection.

Prevention of WNV Infection During Pregnancy

Pregnant women should apply insect re-

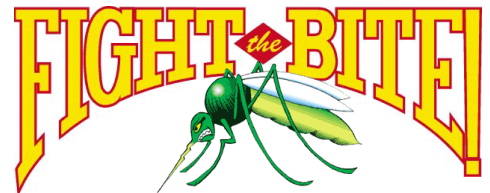
pellent, containing DEET, to clothes when exposed to mosquitoes and wear clothing that will help protect against mosquito bites. Spray insect repellent on clothing in order to minimize direct skin contact. Apply insect sprays or lotions to skin sparingly. In addition, whenever possible, pregnant women should avoid being outdoors during peak mosquito-feeding times (i.e., usually dawn and dusk), and take precautionary measures for mosquito abatement emptying all standing water in and around property.

MMWR February 27, 2004: 53(07): 154-156

Should you have any questions or need further information about testing or interpretation of test results regarding WNV, please contact:

Utah Department of Health
Health Resource Line
1-888-222-2542
<http://health.utah.gov/wnv/>
Bureau of Epidemiology
1-801-538-6191

Pregnancy RiskLine
1-800-822-BABY (2229)



References:

Werler, M., McCloskey, C., Edmonds, L.D., Olney, R., Honein, M.A., Reefhuis, J., "Evaluation of an Association Between Loratadine and Hypospadias." MMWR 53(10): 219-221.

Kallen B., "Use of antihistamine drugs in early pregnancy and delivery outcome." J Matern Fetal Neonatal Med 11(3): 146-52.

Update on UBDN Center Study

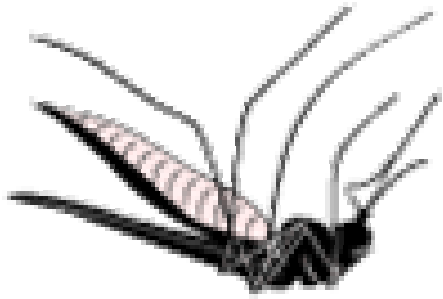
In December 2003, the Utah Center for Birth Defects Research and Prevention (UCBDPR) began interviewing Utah mothers. The Utah Center is part of the National Birth Defects Prevention Study (NBDPS), which has been active in eight other states for six years. Researchers are now analyzing the data collected, and research results are beginning to be published.

One of the purposes of the national studies is to respond to public health concerns. In 2002, a MMWR report was

published showing an association between Loratadine (Claritin®) and hypospadias (Kallen, 2002). Using NBDPS study data, the Centers for Disease Control and Prevention was able to respond to the Food and Drug Administration's request to examine these same factors on a different population. The study data showed no association between Loratadine use early in pregnancy and hypospadias (Werler, 2004).

For more information about the NBDPS, contact Amy Nance at aenance@utah.gov or 1-866-871-1586.

Important Information About West Nile Virus



- West Nile Virus is expected to hit Utah this summer.
- We estimate more than 41,000 women will be pregnant during the peak season (July-September).
- The risk to a pregnant woman and her fetus are not well defined, but may be of concern.
- See inside (page 3) for details regarding clinical information and guidelines for testing.

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